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# IthaMaps Submission Form

(please return the completed form to petrosk@cing.ac.cy)

**COUNTRY:**

**A. Contributor’s details**

**(to be included in ITHANET Organisations & Experts)**

|  |  |
| --- | --- |
| **Name** |  |
| **Surname** |  |
| **Title** |  |
| **Expertise / research interests** |  |
| **Address** |  |
| **E-mail address** |  |
| **ORCID, if available****(**[**http://orcid.org/**](http://orcid.org/)**)** |  |
| **ResearcherID, if available****(**[**http://www.researcherid.com/**](http://www.researcherid.com/) **)** |  |
|  |  |
| **Organisation’s name** |  |
| **Organisation’s brief description** |  |
| **Organisation’s address** |  |
| **Organisation’s website** |  |

**Note:**

The information you provide for the specific country will appear on the IthaMaps website and your contribution will be acknowledged.

**B. Healthcare policies**

|  |  |  |
| --- | --- | --- |
| **Health-policy** | **Select ONE Answer** | **Comment** |
| Prevention programme | YES (National)YES (Regional) NO |  |
| SCD Newborn Screening | YES (National)YES (Regional) NO |  |
| Prenatal Screening | YES (National)YES (Regional) NO |  |
| Antenatal Screening | YES (National)YES (Regional) NO |  |
| Haemoglobinopathy patient registry | YES (National)YES (Regional) NO |  |
| Rare disease patient registry | YES (National)YES (Regional) NO |  |
| Dedicated treatment centres | YES (National)YES (Regional) NO |  |
| Blood transfusion availability | YES (National)YES (Regional) NO |  |
| Iron chelation availability | YES (National)YES (Regional) NO |  |
| MRI facilities | YES (National)YES (Regional) NO |  |
| Patient associations | YES (National) YES (Regional) NO |  |
| Genetic counselling | YES (National)YES (Regional) NO |  |

**C. Status of major haemoglobinopathies**

|  |  |  |
| --- | --- | --- |
| **Haemoglobinopathy** | **Provide Value** | **Comment** |
| Prevalence of β-thalassaemia carriers | % of the population |  |
| Prevalence of sickle cell disease carriers | % of the population |  |
| Prevalence of α-thalassaemia carriers | % of the population |  |
| Prevalence of Hb E carriers | % of the population |  |
| Prevalence of Hb C carriers | % of the population |  |
| Expected incidence of β-thalassaemia  | # of expected affected births / year ***(without prevention)*** |  |
| Expected incidence of sickle cell disease  | # of expected affected births / year ***(without prevention)*** |  |
| Incidence of β-thalassaemia  | # of affected births / year ***(after prevention)*** |  |
| Incidence of sickle cell disease  | # of affected births / year ***(after prevention)*** |  |
| Incidence of Hb H disease  | # of affected births /year |  |
| Known β-thalassaemia patients  | # of patients |  |
| Known sickle cell disease patients  | # of patients |  |
| Known Hb H disease patients  | # of patients |  |

**D. Mutation Frequencies**

Please provide details about publications reporting mutation frequencies in the country of reference (either country-wide studies or region-specific studies).

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**E. Comments/ suggestions about IthaMaps or the ITHANET Portal in general**

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**THANK YOU FOR YOUR CONTRIBUTION**